

The condition and care of AIDS victims in Ghana : AIDS sufferers and their relations



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So far substantial effort has been devoted to the basic research necessary for AIDS prevention and rightly too. What to do with the AIDS patients, the ultimate victims of the human immunodeficiency virus (HIV), until very recently, had remained almost exclusively the concern of health workers. Sufferers continue to be 'guinea pigs' in the hands of scientific and medical researchers in their frantic efforts to find a cure for the disease. But the long incubation period of the disease means that, even if all HIV transmission were to halt immediately, the number of AIDS cases would continue to grow during the next decade at an average rate of ten per cent a year (Panos Dossier 1992). That aside, the number of AIDS-related deaths in some places has already reached alarming proportions, and the impact on families is already manifesting itself in many ways: increasing numbers of orphans, broken families, collapsing family enterprises, loss of family income, growing number of child-headed households, etc. (see Barnett and Blaikie 1992).

In economically depressed countries the strain on limited resources has begun to show as inadequate personnel and facilities have to be syphoned off to take care of AIDS patients. The message is quite clear: it is time to look at the other end of the continuum - the AIDS sufferers. It has, thus, become important now to expand discussion of AIDS to include its more general social consequences. In the early years of the epidemic in Africa, Jonathan Mann, the first co-ordinator of WHO's worldwide AIDS program, commented in an interview on German television that African societies had some advantages over Western industrial countries in that AIDS patients would not be isolated, and that their families would look after them. Thus in Africa, the condition of the AIDS sufferer will be better appreciated if it is looked at within the framework of the family.

Until very recently, much of what was known about the consequences of AIDS to the family was largely anecdotal, as very little research had been done on it. One reason for this inattention to the family and household consequences of AIDS might be the presumption that AIDS is first and foremost an individual disease: that is, the chain of HIV exposure, infection, disease, and death is obviously an individual phenomenon (Eberstein et al. 1988).

Eberstein et al. (1988) believe that there are at least three reasons which make the family or household-level observation significant. In the first place, the primary avenues of HIV exposure do occur in a family context: sexual relationship, pregnancy and childbirth, and breastfeeding to some extent. Secondly, the responsibility for care and support, especially in Africa as already mentioned, rests to a greater extent on the family and kin. Finally, in all societies the family or household is the important interface between the individual and the society. For example, if individuals are shunned or ostracized, either socially or economically, the family bears the brunt of the stigma and its consequences.

Traditionally, illness and health have been held to be a moral and social, rather than an individual and private, affair. This is because it is believed that a person falls ill because of sins of commission or omission against the gods and the ancestral spirits who are believed to

have a direct link with the living, that is the whole society. Often the breach of taboos affecting the gods and spirits is believed to lead to severe mystical penalties with repercussions on the family and the general society. The healing of the sick, therefore, makes use of ritual support involving a healer and some relatives of the sick person designated by the patient's family head.

Lloyd (1988) has conceptualized that the discovery of a person's HIV status or diagnosis of AIDS has profound and disruptive effects upon other family members and their capacity for problem solving. He believes this disruption, while expressed differently, occurs in all cultures. Lloyd maintains that the extent and duration of family disruption, among other things, are influenced by attitudes about HIV and AIDS. Everywhere HIV infection and AIDS have been associated with shame and stigma. Shame, which is described as a powerful emotion, is seen as a central aspect of disruption experienced by both the HIV-infected person and members of his or her family (Lloyd 1988).

More than any other disease, AIDS has the potential to undermine both the social and economic fabric of communities because its victims are those in the economically-active age group and because its spread depends on the way individuals relate to each other. In Africa, including Ghana, AIDS is transmitted heterosexually which may involve spouses or potential spouses. It is estimated that about five-sixths of all seropositive females in the world are to be found in Africa south of the Sahara. In Ghana seven out of every ten AIDS sufferers are females. Another feature of the disease in sub-Saharan Africa is the high rate of infection in pregnant women. The implications for perinatal infection and elevated infant mortality could have a devastating impact on the fabric of society. A traditional Ghanaian belief sees the woman as the pivot of the family and hence it is said that the death of one's mother is the demise of one's family. This notion may derive from the multiple roles of women in the society and family: as health care providers, educators, wives, mothers and income providers. It may thus be aptly said that the AIDS epidemic in Ghana, and indeed the whole of Africa, is very much a family matter.

The few studies that have been done on the impact of AIDS show that the disease has the potential to affect adversely entire communities by threatening their collective abilities to cope. Social systems which are extremely important in maintaining the normality of day-to-day life for most African people are being challenged, stressed and possibly changed by the epidemic. Reports on some communities in Uganda say that if there is no one to look after a man's children after his death,

women who have severed relationship with the deceased man, either through desertion or divorce, may now reappear on his death to look after his children from later relationships (Barnett and Blaikie 1992).

In badly affected areas of Uganda three-day wakes are giving way to shorter funeral ceremonies. Some of the social networks which are active in contributing to the funeral expenses of relatives and neighbours, helping pay for health care, taking on work on neighbour's fields, caring for the sick and looking after orphaned children are losing some of their capacity to absorb the demands imposed by AIDS. Such developments certainly will have powerful influence on the society's attitudes and perceptions about the disease and in turn either reinforce existing stigmas or generate new ones.

Other studies have observed that AIDS patients are cared for by their families with the greater majority of the burden borne by women, wives, mothers, sisters, daughters, aunts and grandmothers (McGrath et al. n.d.; Ankrah et al. 1992:113). AIDS tends to weaken relationships with non-relatives. The family turns in on itself as neighbours reduce contact with its members because of the shame attached to the disease. Other inconclusive evidence

also shows that AIDS has a major effect on the farming household economy and more generally on household incomes.

Within the constraints of grossly inadequate data some estimates have been made of the most immediate financial impact of the pandemic on health budgets. In 1990, the cost of treatment for the global total of people with AIDS - some 200,000 to 300,000 patients - was estimated at US\$2.6 billion to \$3.5 billion. While 84 per cent of the expenditure was accounted for by industrial countries, only two per cent of spending was in Africa which had 50 per cent of all patients with AIDS (Cameron and Tarantola 1992). The low expenditure figure for treatment in Africa is not surprising given that many countries in the continent spend an average of US\$5 or less per person per year on medical care. The result is that many countries are under severe strain in trying to cope with the disease (Merritt, Lyerly and Thomas 1988) and that explains why families are shouldering much of the burden. There is also a psychological side to it, for hospitals in Africa face more than financial strain. The strain on staff of helping people die with dignity (if possible), instead of curing them, can be enormous. Given the vulnerability of most household economies in Ghana, which is a reflection of the national economy, the actual and potential socio-economic effects of AIDS require careful monitoring if some of the severe downstream effects are to be mitigated or avoided.

Since the first case of AIDS was diagnosed in Ghana in March 1986, the number of cases has been increasing at a remarkable rate. By July 1991, 4,824 HIV seropositive patients had been diagnosed in the country, of whom 2,525 were AIDS patients. By 31 December 1992 a cumulative total of 10,285 cases had been officially reported, rising to over 12,000 by July 1993. As elsewhere in Africa, there is underdiagnosis, under-reporting and incomplete recording of AIDS cases: the current level of recording is estimated at 40 per cent. The complete absence of data on AIDS-related mortality makes it impossible to arrive at quantitative measures of the impact of the disease. However, field observations indicate that the death of people with AIDS-like symptoms is becoming widespread. A more prudent approach is to get an impression of the situation now before it reaches a crisis point. The report that follows is a small beginning in this direction. The aim of the study is to look at the way some of the households in Ghana that are currently caring for AIDS sufferers are coping with the situation, and how this affects the social, economic and physical condition of the AIDS sufferers.

Methodology

The main source of data for this study was a fairly large survey on the Social Dimensions of AIDS in Ghana, the fieldwork for which was undertaken from 1 to 24 March 1992. As part of the survey, data were collected about AIDS sufferers and their relations. Through regional and district AIDS counsellors and co-ordinators a total of 141 AIDS patients were located and interviewed in eight out of the ten regions of the country. In addition, 122 relatives or carers of the AIDS sufferers were interviewed with a different questionnaire. The idea was to match AIDS sufferers with their relatives and carers, but some of the latter did not agree to be interviewed. The selection of the samples was mainly purposive interviewing of only those who agreed to co-operate. Most of the interviewing was done in the hospitals where the patients went for routine checks, and a few others were interviewed in their homes.

After the main survey it was necessary to go back to the field for clarifications of certain issues because the AIDS epidemic is a new experience and people are still learning how to come to terms with it. The result was a third set of data on the households of AIDS sufferers from a pilot survey conducted in three areas of the country. The areas were Agomanya in the Eastern Region of Ghana, currently one of the areas known to have a very high prevalence

rate of the disease, Tamale in the Northern Region, a very low prevalence area according to the official records, and Accra, the national capital and a converging point for people from all over the country.

The essence of the supplementary survey was to have a better understanding of how households are coping with the presence of a member who has AIDS. The idea was to interview the head of household, or the person caring for the AIDS patient if he or she was different from the head, in the home. In Agomanya this was easy because the Catholic hospital in the town is running a home-based care service for AIDS patients. In Accra, in the absence of a well-established home-based care system, relatives of patients were traced at the hospital where they came with the patients for routine checks and counselling. The situation was a little different in Tamale and its environs. It was not easy locating the patients. The stigma attached to the disease in that part of the country is very strong indeed. The traditional practice of vetting a family to ensure that it has a clean record and that no member has ever had a dangerous disease before allowing a son or daughter to marry into it is still adhered to. As a result, AIDS patients are either taken into hiding or rejected by the family of which they are members. Tracing the AIDS patients to their households, therefore, was extremely difficult. It would have been easier to trace the relatives of patients who came to the hospital but unfortunately these hospitals were not functioning as a result of industrial action by nurses. Nevertheless, the regional AIDS co-ordinator in Tamale used his personal contacts to identify potential respondents. The selection of respondents for interviewing was purposive, depending heavily on AIDS counsellors and co-ordinators in the areas for the necessary contacts. In all, 93 households were interviewed, 19 each in Accra and Agomanya and 55 in Tamale and its environs. More respondents were recorded in Tamale despite the problems mentioned above because the area of coverage was bigger and the interviewing period was longer, three weeks as against one week each in Accra and Agomanya. As part of the survey on the households of AIDS sufferers, structured conversations were held with AIDS counsellors and co-ordinators in two of the areas of study, Agomanya and Tamale. The conversations were taped and later transcribed.

Results

AIDS sufferers and their relatives: personal characteristics

About 72 per cent of the patients were females, which compares favourably with the national proportion of 74 per cent of AIDS victims. They were relatively young with 77 per cent in the age range 20-29 years, which may be compared with the national figure of 74 per cent. In contrast, only 34 per cent of the relatives of the sufferers are in that age group. If we take the relatives to represent the non-infected general population then the highly age-selective nature of HIV/AIDS infection comes out clearly.

Only 26 per cent of the AIDS sufferers had no formal education. Females were more likely than males to have no education (32% versus 12.2%). The majority (64%) have basic education, primary and junior secondary school level. By comparison, a little more than half of the sufferers' relatives (50.8%) had had no formal education.

It appears that the AIDS patients are a little better educated than their relatives. Again if we take the relatives to represent the non-infected general population then we may conclude that in Ghana AIDS infects the educated. However, this might not be the case because of the way the respondents were selected. It has been stated that most of the respondents were interviewed as they accompanied their sick relatives to the hospital. It is most probable that the less educated in the families were delegated to accompany their sick relatives because they might be self employed and therefore could afford to stay out of work. About 60 per cent

of the sufferers said they were gainfully employed compared with 91 per cent of their relatives. The work of both categories of respondents was mainly in commerce, farming and crafts.

Both categories of respondents were mainly Christians (77% and 82% for the sufferers and their relatives respectively). A few were Muslims (9% and 6% respectively) and a significant proportion said they had no religion (14% and 7% respectively). About a quarter of the patients were married, 17.7 per cent were divorced and another 11.3 per cent were separated. Only one person mentioned that her marriage broke up because she had AIDS. By comparison, about 60 per cent of the relatives were currently married. Just about 7 per cent had never married. Most of the marriages of both samples were contracted by customary rites with consensual unions making up 12 per cent of the marriages of the sufferers. About 46 per cent of all the ever married sufferers have been married twice or more, the mean number of times married being 1.7. For the relatives, a little less than a third have married twice or more, the mean number of times married being 1.4. That means the AIDS sufferers, although younger, are a little faster at marriage than their older relatives. The reasons given by the AIDS sufferers for the breakup of previous marriages included lack of proper care, husbands' promiscuity, infertility and wives' infidelity. Four of the married men affirmed that their wives also suffer from the disease. Two of these wives live in the same town as the husbands, one lived in another town and one had died. Similarly, two of the married infected women said their co-wives also had the disease.

About 55 per cent of the seropositive respondents were of urban origin. Their geographical spread in the country is very similar to the picture portrayed by the national figures. The largest proportion (32.6 per cent) came from the Eastern Region, followed by the Ashanti Region with 15.6 per cent. Brong-Ahafo and Central Region follow with 13.5 per cent each.

Sources of income and financial support

To some extent, the data underscore the notion that in Africa AIDS is a family matter. HIV/AIDS is known to affect the most economically active population most of whom are their families' breadwinners (Panos Dossier 1992). One immediate impact of the disease is that the victims become financial burdens on their families. The data showed that about 56 per cent of the patients were still depending on their own sources of income. By comparison, 92 per cent of their relatives said they depend on their own sources of income. Most of the rest of the sufferers depend on other members of the family, mainly parents and siblings. Only 5 per cent said they depend on spouses and a few (2%) depend on friends. The two sets of data at least give some idea of the dependency burden on relatives of AIDS sufferers which is a result of the disease.

Despite the evidence of some family support, most of the patients seem to experience some financial crisis. When asked to describe their income, only a quarter said it was at least adequate. The rest described their income as inadequate. In fact, a majority of them (60%) reported that they need to rely on others for additional help. Assistance was mainly in the form of food and general needs as well as the payment of hospital bills.

Knowledge of AIDS and transmission routes

The study sought to know whether the patients had heard of AIDS before their diagnosis. Awareness of the disease was high, with 89 per cent having heard of it as against 87 per cent of their relatives. However, the figures were strikingly lower than that obtained in a recent national KAP survey, 99.4 per cent (McCombie and Anarfi 1991). The mass media were the most important sources of information (68% for patients and 53% for the relatives). Other

sources were friends, relatives and health workers. The indication is that the educational campaign on the disease has made an impact and must continue.

Knowledge of AIDS transmission was characterized by high recognition of transmission through sex, with 80 per cent of the patients and 76 per cent of their relatives giving this as the response. Many fewer mentioned transmission by blood transfusion and genetic transmission. They tend to have few misconceptions. Coming after their post-diagnosis counselling the level of knowledge of the AIDS patients about the disease is not surprising.

Post-diagnosis reactions

Lloyd (1988) has conceptualized that when a person is discovered to have HIV/AIDS, the infected person and family members experience a post-diagnosis process of shock, blow, recoil and recovery. He explained that if the family and the HIV-infected person can pass through all the steps in this process, there are good prospects for mutual support, expression of love and acceptance. Otherwise the family will tend to ignore or reject the infected member. The present study attempted to see where the generality of Ghanaian families with AIDS-afflicted members could be placed on the continuum.

Almost all the patients got to know about their ailment after tests in the hospital where they reported sick. Just about two per cent learnt of their situation after blood donation. In fact most AIDS cases in Ghana are detected symptomatically. The first reactions on hearing that they had the disease were shock (41%), sorrow (33%), fear (8%) and anger (1%). A few (11%) were indifferent.

Hospitals and clinics ranked highest (86.6%) among the first places patients went for treatment on hearing that they had the disease. They are followed by traditional healing (8.5%) and then spiritual or faith healing (1.4%). As the disease persists, patients seem to lose interest in all forms of treatment involving medication. For example, in the subsequent search for cures, preference for hospitals or clinics dropped to 38.3 per cent and that for traditional healing to only 3.5 per cent. Preference for spiritual healing, however, increased dramatically to 9.2 per cent.

This development may not be unconnected with the fatal nature of the disease. Conscious of the fact that death awaits them, patients may want to try that which sees beyond this life. The flight may also be connected with the indignity and frustration of being an AIDS patient within the existing health care system in Ghana.

Once HIV-status is known to a person, he or she must undergo the stress of deciding when or whether to tell the family. The difficulty stems from the feeling of shame as knowledge of HIV-status invariably leads to revelation of behaviours or practices which heretofore were unknown or were denied and not discussed by family members. About a quarter of the patients did not tell anybody after the diagnosis. A little over one-third informed their mothers and another 21 per cent informed siblings. Only seven per cent informed spouses, confirming observations in Eastern and Central Africa that some patients do not inform their spouses (see Barnett and Blaikie 1992). Nonetheless, it is heartwarming to note that the family provides the opportunity for AIDS patients to come out.

Reactions of others to the patients

In his concept paper Lloyd (1988) remarks that 'positive HIV-status and AIDS creates a family disruption which is pervasive and enduring. It is felt at all levels of individual and collective life within the family' (p.184). The patients were asked about the initial reaction of the various family members on hearing of their disease. As expected, most of the relatives were shocked (24%), or sad (23%) when they were told of the disease. A few (7%) were angry but some (6%) did not believe it. The reactions of spouses on hearing of the disease

were interesting. About 31 per cent were just outraged or indifferent. About six per cent of the respondents could not tell the mood of their spouses. Only 30.8 per cent could say specifically that their spouses were sympathetic.

Similar reactions were exhibited by fathers. However, the proportion that was sympathetic went up to 39 per cent, 14.8 per cent were outraged and 5.4 per cent were unsympathetic. Most mothers were quite sympathetic (74%) which underscores their natural role as care providers. Nonetheless, the proportion of mothers who were outraged (20%) was quite significant. Such is the threat AIDS poses to the hitherto closely knit African family system. Cracks seem to be appearing in the fabric.

The reactions of brothers and sisters were quite reassuring. About 48 per cent and 62 per cent respectively were sympathetic and 23 per cent and 6.2 per cent in the same order were indifferent. But siblings can afford to be sympathetic or indifferent. Society does not expect them to shoulder fully the responsibility for caring for a sick relative, particularly if parents are around. They always come in as extra hands. Other relatives and friends were more sympathetic than otherwise. Patients could not easily assess the reaction of neighbours and the community and most of them answered 'no idea'. This may be explained by the fact that AIDS patients have very little interaction with non-family members of the community.

When respondents were asked about the current reaction of family members to the patients' predicament interesting changes were observed. It seems the initial negative reaction to the news of the diagnosis wanes as the disease progresses. This is demonstrated by the increased proportion of the categories of family members who were sympathetic to the patients at the time of the interview. For example, the proportion of sympathetic spouses had increased to 50 per cent and that of mothers to 89 per cent. The wasting nature of the disease could have a powerful influence on people's emotions just as the effects of wars and famine have. Also, the traditional belief in the link between the living and the spirits of the dead could compel some people to be sympathetic to critically ill relatives. People do not want to incur the wrath of a dying person fearing that the spirit of the deceased would take revenge.

The care and condition of patients

The care of the patients rests almost solely with blood relatives, mainly parents, siblings and children. The responses of the relatives of AIDS sufferers to the question 'Why are you the person looking after the sick relative?' show that they see it as an obligation. Some of them said they were looking after their sick relatives because they are parents, family heads or husbands, or because there is no one to look after the sick ones. This stresses the fact that African societies see the sickness of a relative as a family matter. Only 9.2 per cent were being cared for by their spouses, while 11 per cent were taking care of themselves. A few were in the care of some religious organizations and hospitals. Some Catholic hospitals in the country have in place some home-based care programs, which involve home visits in the towns and their surrounding villages by health workers and some church people. Patients and their relatives are counselled during such visits and they are given supplies of drugs and other essential items.

The majority of the AIDS patients (80%) affirmed that they are satisfied with the type of care being given. It involved general care which included administration of medication, physical and social support and financial assistance. When asked to state whether or not they expected any other things 39 per cent answered 'nothing'. In terms of their main reaction to the situation in which they found themselves, some said that it was the pain and sickness which dominated their life, others reported that it was their shame and regret and still others referred mostly to their boredom at being largely confined. However, when asked about their greatest problem, the majority pointed to lack or insufficiency of medicines to cure them, to reduce their symptoms or to make life more comfortable; and the need for balanced diet.

The 'no expectation' response may be a sign of hopelessness that brings to the fore the observation by Katoff and Ince that

Before very recently most people who received the AIDS diagnosis felt that life was over. That there would be no more opportunities; no more career; no more chance for love. Many felt as if they were already dead, emotionally if not physically (Katoff and Ince 1991:544).

Coping with the AIDS afflicted

Provision of health care

The day-to-day care of the patients at home is the sole responsibility of the members of the family, mainly parents, siblings, children, uncles and aunts. Only eight wives are taking care of their sick husbands. Interestingly, no husband is taking care of a sick wife. Painfully, most of the households showed many reservations in the care of their sick relatives. For example, a young woman aged 20 years had been abandoned by the whole family but her mother. She had her own drinking cup, plates, bucket for washing and other things. She relieved herself in a receptacle in her room partly because she was too sick to move and partly because she was not welcome at the public toilet in the village (see Awusabo-Asare and Agyeman 1992). In another case, the patient had been locked in her room and food was passed to her under the door.

Most of the households provide medical treatment for their sick relatives, 13 per cent give both medical and herbal treatment, four per cent give only herbal treatment and only one receives spiritual healing. However, most of the patients were not in the hospital at the time for various reasons including the strike by nurses and what the respondents termed embarrassment to the family.

The AIDS patient in the household

Households did everything to stand up to the strain of having an AIDS sufferer among them. In fact the majority of the households (53%) said the sickness of their relative had not had any effect on the household structure. Nevertheless, there was often suspicion of contamination and fear of using the same eating vessels. In the northern part of the country some patients were shut away in the room because of the feeling of shame and embarrassment. In this area some patients in hospital, mostly women, have been abandoned by their relatives. About 13 per cent of the households mentioned that their households have been disorganized and another five per cent said they have been reduced in number. The concern of most of the AIDS-afflicted households was that they get very little or no help from the state and the sick have become a burden on the families.

Reporting to the hospital

Some of the patients report to the hospital alone but many go with their relatives. They often go with persistent headache, coughs and diarrhoea which do not respond to treatment. In the Northern Region, those who go to the hospital alone are those whose relatives already suspect that they are suffering from the disease and, therefore, do not want to associate with them. They are normally at the terminal stage of the illness. In Agomanya patients do not often come alone. There is, however, the practice of leaving the patient alone for a while after some time as the relatives go to look for money with which to cater for them.

Abandonment

In the Agomanya hospital there have been two cases of abandonment so far. They involved women about the age of 30 years. In the North there are a few patients who have been neglected by relatives, some even to the point of refusing them shelter. Some of these ended in the hospital and became the hospital's responsibility. In this hospital about five per cent of AIDS patients are abandoned cases. They are often those whose moral behaviour, in the eyes of their families, is questionable. Their relatives feel they are a disgrace to the family. All the abandoned cases in the Tamale hospital so far have been women.

With no money coming from the AIDS Control Programme, abandoned cases become a financial burden to the hospital. As their diseases are not curable they are treated symptomatically. Now that Ghanaian hospitals are operating the cash-and-carry system it is sometimes difficult to get the routine drugs for the patients. More often than not 'these people are almost dying so we just leave them to die though we know we should be doing better than we are doing', reported an informant.

Handling the sick in the hospital

AIDS patients are given treatment according to the symptoms they present in addition to counselling. In the northern part of the country the hospital feeds the patients because they need a balanced diet. In the handling of the patients the hospitals encounter some problems, some relative to the patients themselves. Most accept the fact that they have the disease but some do not and often attribute it to evil spirits. For such people counselling becomes a problem and they are often difficult to handle. Other problems include lack of financial support, the social stigma attached to the disease (people do not want to associate with them; they are often deserted and that alone kills them fast), and denial by relatives of their wards having AIDS.

The Catholic hospital at Agomanya gets some assistance from the National Catholic Secretariat and other foreign agencies associated with the church. The government hospital in Tamale gets no assistance from anywhere. It is the Planned Parenthood Association of Ghana that helps with information, education and communication (IEC) programs.

In Agomanya the average number of beds occupied by AIDS patients at a time is about three per week out of a total of about 40 beds. In Tamale the rate is about four beds per week out of 100-odd beds. In the former, protective items like gloves, boots, etc. are provided to health workers who handle AIDS patients. There are none in the latter, a much bigger government hospital. Both places lack transport.

The average cost of treating an AIDS patient is around 50,000 cedis (about US\$100), more than twice the monthly salary of the average Ghanaian at the time of the survey. The ratio of the cost of treating an AIDS patient to other outpatients is about 5 to 1. The treatment cost covers drugs, facilities used and food. The relatives of those who are not abandoned pay for these charges and the patients who can afford it pay for themselves. In Agomanya patients with full-blown AIDS are treated free of charge and the cost of treatment for HIV patients is subsidized. In the government hospital in Tamale if the patient cannot pay he or she is kept in the hospital and is given whatever the hospital can afford which is often not enough.

Conclusions and policy implications

One advantage Ghana has over most of its West African neighbours is that it took an early start in the control of AIDS by coming to accept it as a major health hazard. Now there is evidence that the level of awareness of the danger posed by the disease has gone up, thanks to the educational campaigns embarked upon by the AIDS control program. The disease itself

has now become firmly established in the country and the rate of spread is increasing remarkably. AIDS sufferers are now visible in some communities and AIDS-related deaths are becoming widespread.

The first people to suffer the impact of the disease are the members of the families of AIDS patients. In the absence of adequate health care facilities families are doing well to cope with their afflicted members. However, there is evidence that some families are experiencing financial crisis as a result of trying to cope with the disease. This, and the strong stigma attached to the disease, are putting a strain on the families and the hitherto close-knit family system is showing signs of cracks to the detriment of the AIDS sufferers.

For a developing country like Ghana this brings out the argument of whether government, in addition to the preventive activities they have rightly embarked upon, should take up or subsidize curative care as well. Although the economic justification for private market curative services appears much stronger, the generally low incomes in the country may make the catastrophic care associated with a disease like AIDS unaffordable to many households. If patients are made to suffer much indignity as a result of neglect by families and the government some HIV-positive people may be forced to go underground and that will endanger the prevention drive. Government must, therefore, subsidize the curative care of AIDS patients. That will give it the power to decide on resource allocation, level of service, and virtually all other aspects of decision-making in health care supply. This will remove any differential in the cost of treatment that may exist between the capital city and the rest of the country.

It is now time to take intervention programs beyond mere awareness creation to include mechanisms for coping with the disease within the family and the society at large. There is certainly the need for social counselling and psychic support. Community education is needed to reduce the level of blame and shame. Families must be helped to accept their sick relatives with love and concern instead of the feeling of embarrassment against the suspicion of neighbours. The expectations of the few patients for better medical care and balanced diet means that they desire to live. This brings into focus the need to put in place organizations to provide emotional and practical support to people with AIDS. Such organizations should provide a kind of lifeline, to serve as a means for a person to re-establish the ability to live fully within the limitations of the illness.

Women seem to be affected uniquely by the disease in Ghana. They are not only in the majority at the receiving end, but also they are at the forefront in coping at the household level. They need special attention in every intervention program. If future strategies to cope with the disease are to succeed, women must be involved in their planning, implementation and monitoring. Women's movements have a role to play here.

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